
Palliative Care-A Service to Improve the Dying Experience in Hospitals and Nursing Homes

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Abstract

The majority of Americans die in hospitals and nursing homes. There is substantial evidence in the medical literature, that care of the dying in such settings is often poor, and the obstacles to providing good end-of-life care remain numerous. Palliative care consultation has the potential to improve the care of patients dying in the institutional setting.

Background

At least two out of three Americans die in institutions, mainly hospitals and nursing homes.

Indeed, hospitals are the most common place to die. It has been reported that 57% of deaths are occurring in hospitals, with some regional variations across the country.¹ At the present time, one out of five Americans dies in nursing homes,² representing half a million deaths each year.³ While hospital deaths are declining slightly, the number of deaths in nursing homes is rising rapidly. It has been estimated that this number will rise from the current 20% to 40% in 2020.⁴ Such changes reflect the recent shift from inpatient to outpatient care, and perhaps a growing preference for less aggressive end-of-life care. The increased number of nursing home deaths has been tied to greater availability of nursing home beds and lower number of hospital beds as well.⁵

End-of-life care has been found to be poor in both hospitals and nursing homes, despite the fact that those are such common sites of death. High rates of untreated pain and other symptoms have been documented in both dying hospital patients,⁶ and nursing home residents.^{7,8} It has been repeatedly demonstrated that 40% of hospitalized patients in a wide variety of disease categories die in severe pain.^{6,9} Other common, although treatable symptoms are dyspnea (50%), delirium (25%), anxiety and depression (25%).⁶ There is also a growing body of literature on the under treatment of pain in nursing homes. One out of four nursing home patients in daily pain were found to receive no treatment.^{7,8} Certain groups, like the oldest-old and minorities, are at particular risk.

Similarly, advance care planning has been found to be absent or insufficient in these settings. A study published in 1998 found that two thirds of nursing home residents have no documentation of advance care planning,¹⁰ and in those who did, it was usually insufficient. Other studies came to similar conclusions.¹¹ Perhaps even more striking is the finding of marked regional variations in the utilization of advance directives by nursing home patients.¹² Organizational features rather than patient and family preferences can influence the utilization of end-of-life care options, such as hospice^{3,13} and advanced directives^{12,14} in nursing homes. Similarly, hospital data indicate that less than half of inpatients discussed advance directives with their physicians.¹⁵ Others found this number to be even less, only one out of four.¹⁶ Given that, it is not surprising that the care provided is often incongruent with patient preferences.¹⁷

The above data illustrate the fact that providing high quality end-of-life care in hospitals and nursing homes remains a challenge. A variety of reasons including organizational, regulatory, reimbursement, educational, and cultural issues are involved.

A successful model of good end-of-life care already exists in the form of hospice. Hospice services have been shown to improve end-of-life care by improving the management of pain and other symptoms, and by providing emotional and social support to the patient and the family.¹⁷ Hospice services are best suited for patients dying from diseases that have a predictable terminal course, like AIDS and cancer, and for patients living at home, and have a dedicated caregiver. Reimbursement is limited to those with less than six months of life expectancy. Given that, it becomes obvious that such a model is not always applicable to patients dying in institutional settings, and from a wider range of medical conditions.

The current state of death in the hospital:

In hospitals, the emphasis is placed on curative care. Yet, hospitals remain the site of death for many, including those with acute and chronic disease, trauma, those dying unexpectedly, and those with limited social and financial resources. The impact of hospital death on patients and families has been well documented in the SUPPORT study.¹⁹ Most notable are the findings of high level of untreated symptoms, poor communication, difficulties prognosticating, deficiencies in advance care planning and decision making, and large family burden. This study has also demonstrated that our current perception of the effective ways for improving care of the dying (better communication, advanced care planning and education) has underestimated the complexity of the problem.²⁰ With many suffering and dying in hospitals, the task of incorporating good symptom

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control and other aspects of palliative care becomes an essential part of good practice. Blending and balancing curative and supportive care is a difficult, yet everyday challenge for those working in hospitals. Barriers to good end-of-life care can be numerous in the hospital setting, including focus on curative care, uncertainties regarding prognosis, lack of knowledge, negative attitudes, financial, quality management and regulatory issues, fragmented care and decision making, legal concerns, etc.^{21,22} There is an emerging understanding that systematic changes are needed for improvement.¹⁷

The current state of death in the nursing home:

In nursing homes, the emphasis is placed on restorative and custodial care,²³ while failing to measure and reward high quality end-of-life care.² While such emphasis is meaningful and appropriate for many, it does not acknowledge the needs of a substantial portion of the nursing home population suffering from irreversible terminal conditions. In fact, the majority of patients get admitted to nursing homes with the expectation that they are going to die there. The oldest and the most frail are the ones most likely to spend the end of their lives in nursing homes, and to die there. There is recognition that nursing homes should be reconceptualized as end-of-life care institutions.²⁴ The fact that the majority of those dying are also elderly is not unique to the nursing home, but is rather a universal phenomenon, making a case for enhanced geriatrics skills for all who provide end-of-life care.²⁵

Interestingly, despite the growing pressure in recent years to reduce hospitalization, financial incentives are still in place for all involved to transfer dying nursing home patients to the hospital.²⁶ Dissatisfaction with terminal care in nursing homes has been documented.²³ Nursing home residents are typically of very advanced age, with multiple, chronic, incurable diseases like dementia, chronic lung and heart disease. Only 1% of dying nursing home residents use hospice services.² Hospice utilization has been low for such patients for a variety of reasons. There are difficulties in prognosticating the terminal course of such patients.²⁸ Most nursing homes do not have regular access to hospice.²³ Efforts to promote such services for nursing home residents and their families have been limited. Widespread interventions and high quality medical research on the common human experience of dying in nursing homes is quite limited.

In addition to being low, there are also wide variations in the utilization and access to hospice care by nursing home residents. Access may be strongly influenced by facility related factors, so low utilization does not necessarily reflect patient preferences. Currently, obstacles to high quality end-of-life care in long term care are also numerous and include lack of expertise and resources, negative public image, burden of administrative work, low staffing, regulatory environment, and lack of social support for some residents. Current health policy, quality standards and reimbursement discourage the use of palliative care and hospice in nursing homes.^{2,3} Incentives are on the side of restorative and technologically intense treatments. In fact, incentives or quality standards specific to the needs of the dying are lacking. As a result, systematic changes in the nursing home industry will be needed in order to improve terminal care.

In summary, the question remains. How are we going to provide

a better dying experience for patients and families in the institutional setting? We need to start by answering the question: what are the features of a "good death"? In fact, there is a growing literature on this subject. Several key points include high quality medical care, ethical decision making, symptom control, emotional and spiritual support, family and caregiver involvement, continuity and planning of care, and attention to patient and family preferences.²⁹⁻³² For all dying patients, the right to such high quality end-of-life care is well-established,³³ and all health care providers have the ethical obligation of providing it. It has been increasingly recognized on a national level that there is an urgent need to correct the existing shortcomings in the care of the dying.³⁴ We need to make such care not only available, but rather routinely offered to nursing home and hospital patients. The role of hospice and palliative care needs to be expanded in the nursing home and hospital setting, as part of an effort to achieve such a goal.

Palliative care consultation

Palliative care consultation is a model that has been increasingly used in an effort to improve end-of-life care in settings like hospitals and nursing homes. Palliative care is "The study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life."³⁵ The benefit of such approach has been established.¹⁸ It includes enhanced quality of life by improved symptom control, emotional and psychosocial support for the patient and family, and coordination of care.^{36,37} In addition to the clinical role of such services, their educational role has been emphasized as well.³⁸

Palliative care consultation in hospitals

Over the past decade, there have been several reports on hospital based palliative care consultation for terminally ill patients.³⁶⁻⁴² They have been mostly geared towards cancer and AIDS patients. Such services were found to favorably impact care. It has been increasingly recognized that they are also beneficial to patients dying from other chronic progressive diseases, such as heart and lung disease, and dementia. While such services are becoming increasingly available, they are still nonexistent in the majority of hospitals. A high quality end-of life care experience is difficult to achieve in such settings due to barriers already discussed. Physicians and staff often lack awareness, and their education is typically insufficient. Patient needs are complex, and reimbursement for palliative care is limited. Yet, there are numerous conceivable benefits from such services, including higher quality of care, better patient, family and staff satisfaction, avoidance of expensive, invasive procedures in patients who are unlikely to benefit, shortened length of stay, and coordinated, more appropriate discharge planning.

Palliative care consultation in nursing homes

For patients dying in a nursing home, often a decision has been made to limit aggressive treatments.⁴³ A palliative treatment plan is essential for such patients. Furthermore, due to the high prevalence of uncomfortable symptoms such as pain, palliative care needs to be integrated into the treatment plan of nursing home patients, regardless of prognosis.

Terminal dementia is the example we would like to use in order

to make the case for widespread palliative care in nursing homes.⁴⁴ Dementia is among the leading medical conditions in the nursing homes, affecting 60% of patients.⁴⁵ Advanced dementia is incurable and fatal. Palliative treatments are central to the appropriate care for patients at advanced stages of a dementing illness, in view of the common, highly distressing symptoms, which include pain, agitation, delirium, delusions, hallucinations, depression, insomnia, dysphagia, malnutrition, incontinence, constipation, pressure ulcers, immobility, and symptoms associated with infections (fever, pain, shortness of breath). The complex psychosocial needs of the patient and family, the suffering of the patient, caregivers and family and the frequent need for ethically challenging decision-making in these patients can also be addressed within the context of palliative care. In reality, despite the overwhelming need, few facilities have the expertise and resources for providing palliative care to their residents,² despite the proven value of such services.⁴⁶ Specialized hospice units in nursing homes are rare.⁴⁷ Administrative structure is often lacking for providing high quality end-of-life care in nursing homes. Staff education is typically insufficient, and educational efforts are erratic, and not tied to more widespread structural changes.⁴⁸ Given the everyday need to deal with death in nursing homes, education in end-of-life care should be considered mandatory. Medical care in nursing homes is typically provided by community physicians, most of whom lack education and training in palliative care. The lack of such expertise and services is likely to contribute to the frequent hospitalization of nursing home patients, which has been well documented.⁴⁹⁻⁵¹ Frail patients, who are the least likely to benefit from hospitalization, are the ones more likely to be hospitalized.²⁶

Few patients desire the hospital or the nursing home as a site of death. Most people want to die at home, in sharp contrast to what happens in reality.⁵² The advantages of a home arrangement include enhanced privacy, patient autonomy, presence and involvement of the family,⁵³ familiar environment, limited use of medical technology, and well established relationships with caregivers. In view of the increasing trend of nursing home deaths, efforts should be made to bring the advantages of the home as a site of terminal care to the nursing home. In fact, the nursing home environment would allow for these fairly easily.

In addition to what has been already said, palliative care consultation can be used in situations when using hospice is difficult. This could happen for a variety of reasons. Difficulty prognosticating the terminal course of many chronically ill patients²⁸ makes providers reluctant to refer to hospice, and hospices equally reluctant to take patients with exceedingly common conditions, such as chronic heart and lung disease, or dementia. Patient and families are sometimes reluctant to give up standard health insurance benefits in favor of the hospice benefit due to personal beliefs and values, or due to financial disincentives related to the arrangement. Lack of access becomes an issue, particularly in cases where there is no contract between the nursing home and a hospice organization. In all these situations, palliative care services can help in fill in the gap.

The value of palliative care goes beyond serving the clinical needs of patients. In the past few years, substantial effort has been made to enhance medical education and research in end-of-life care. With medical education having its traditional emphasis on curative, hospital based medicine, physicians are insufficiently trained to

comprehensively manage patients near the end-of-life. If such patients reside in a setting other than a hospital, the physician is less likely to have received training in this area. This has been well recognized, and reported by the Consensus Conference on Medical Education for Care Near the End of Life in 1999.⁵⁴ Educational efforts are needed in targeting all levels of health professionals, including medical students, residents, faculty, practicing physicians, and allied health professionals. There are unique educational opportunities offered by palliative care including symptom control, patient management in settings other than inpatient, interdisciplinary work, ethics, dealing with family and caregiver issues, communication, goal setting and clinical decision making, etc.⁵⁵ The opportunities and the value of palliative care education has been recognized both in the hospital,⁵⁶ and long term care settings.⁵⁴

Since the landmark SUPPORT study,¹⁹ the experience and the care of those dying in an institutional setting has been increasingly recognized as an important area of medical research. While SUPPORT gave an important insight to the state of dying in American hospitals, many questions remain unanswered. Despite the fact that nursing home deaths are so common, there has been little research done on the topic. Further clinical studies and health services research are needed.

In summary, there is a great need for providing better palliative care services to those dying in health care institutions like hospitals and nursing homes. Since the overwhelming majority of those dying are elderly, more geriatrics expertise is also essential for providing better end-of-life care.²⁵ This perhaps applies to Hawaii even more than other areas of the country, given the fact that life expectancy is high,⁵⁷ hospice utilization is low,⁵⁸ and there is a shortage of nursing home beds.

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